

# Review of acute rheumatic fever and rheumatic heart disease among Indigenous Australians

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1. Australian Indigenous HealthInfoNet

No 14. October, 2013

## Suggested citation

Gray C, Thomson N (2013) Review of acute rheumatic fever and rheumatic heart disease among Indigenous Australians. Australian Indigenous HealthInfoNet.

This review - or an updated version  
can be viewed at:

[http://www.healthinfonet.ecu.edu.au/rhd\\_review](http://www.healthinfonet.ecu.edu.au/rhd_review)

## Preface

This review of acute rheumatic fever and rheumatic heart disease among Indigenous Australians has been prepared by the Australian Indigenous HealthInfoNet as a part of our contributions to 'closing the gap' in health between Indigenous people and other Australians by making relevant, high quality knowledge and information easily accessible to policy makers, health service providers, program managers, clinicians, researchers and the general community.<sup>1</sup> The review is an example of the HealthInfoNet's translational research [2], defined as 'comprehensive applied research that strives to translate the available knowledge and render it operational' [3, p.1794].

The main purpose of the review, which follows the model of narrative reviews/syntheses [4], is to provide an authoritative, up-to-date review of acute rheumatic fever and rheumatic heart disease among Indigenous people that: (1) is a valuable overview for people working in the area; and (2) assists in the development/refinement of policies, strategies and programs.

Research for the review involved the collection, collation, and analysis of a wide range of relevant information, including both published and unpublished material. Sources include the full range of relevant literature, including journal articles and other

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1 The term Indigenous is used in this review to refer generally to the two Indigenous populations of Australia – Australian Aboriginal people and Torres Strait Islanders.

relevant publications, the vast majority of which are accessible via the HealthInfoNet's Australian Indigenous HealthBibliography. This bibliography, with more than 20,000 entries, captures all relevant journal articles, books, book chapters and reports (including the 'grey' literature).

As well as the relevant journal literature, the HealthInfoNet's reviews draw on important government reports, particularly those produced by the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW) and the Steering Committee for the Review of Government Service Provision (SCRGSP), and reports in the Aboriginal and Torres Strait Islander health performance framework series. These reports, prepared by the Australian Health Ministers' Advisory Council (AHMAC) in 2006, 2008, 2011 and 2012, are accompanied by substantial detailed analyses, which are accessible on the AIHW website. The HealthInfoNet's reviews also draw on information from the main administrative data collections (such as the birth and death registration systems and the hospital inpatient collections) and national surveys. Information from these sources has been published mainly in government reports, particularly those produced by the ABS and the AIHW.

After providing the context of acute rheumatic fever and rheumatic heart disease, the body of the review outlines the extent of acute rheumatic fever and rheumatic heart disease among Indigenous people, provides an overview of the various contributing factors, considers prevention and management, summarises a number of relevant policies and strategies, and provides some brief concluding comments. Rather than commence with an executive summary, the review is preceded by a section devoted to 'Key facts', which presents the summarised information in a more concise form.

Further information about acute rheumatic fever and rheumatic heart disease among Indigenous people is accessible from the relevant section of HealthInfoNet's web resource ([www.healthinfonet.ecu.edu.au](http://www.healthinfonet.ecu.edu.au)), which provides access to: the complete Indigenous-specific literature; details of policies and strategies, programs and projects, and organisations involved in the area; and databases of health promotion and health practice resources. The section also contains a plain language version of this review.

We welcome your comments and feedback about the review.

Neil Thomson, Director, on behalf of the HealthInfoNet team

## Acknowledgements

Particular thanks are extended to:

- Dr Keith Edwards, Community Paediatrician, Darwin, and Senior Lecturer in Child Health, Flinders University, for his valuable guidance in the development of this review
- other staff of the Australian Indigenous HealthInfoNet for their support and encouragement, with special thanks to Leah Levitan for preparation of the review for publication
- the Office for Aboriginal and Torres Strait Islander Health (OATSIH) within the Australian Department of Health and Ageing for their ongoing support of the work of the HealthInfoNet.

## Key facts

### Indigenous population

- At 30 June 2011, the estimated Australian Indigenous population was 669,736.
- NSW had the highest number of Indigenous people (208,364, 31% of the total Indigenous population); the NT had the highest proportion of Indigenous people in its population (30% of the NT population are Indigenous).
- In 2011, the majority of Indigenous people lived in cities and towns; around one quarter of Indigenous people lived in remote or very remote areas.
- The Indigenous population is much younger than the non-Indigenous population.

### Acute rheumatic fever

- Acute rheumatic fever (ARF) and new cases of rheumatic heart disease (RHD) are almost exclusively experienced by Indigenous people in Australia; Indigenous children and young adults are most affected by ARF and RHD.
- There were 317 notifications of new and recurrent cases of ARF in the NT in 2005-2010. Of these cases, 311 (98%) were Indigenous people. Recurrent cases made up 24% of all cases. Almost two-thirds (58%) of the Indigenous notifications were for children aged 5-14 years.
- The rates for ARF were highest for Indigenous females in the 5-14 years age group. Indigenous females accounted for more notifications for ARF than Indigenous males among those aged 5 or over.

### Rheumatic heart disease

- In 2010, in the NT, there were 1,479 cases of RHD on the register. Almost all cases involved Indigenous people (1,379 cases (93%)). After age-adjustment, rates for Indigenous people were 26 times higher than those for non-Indigenous people.

### Hospitalisations for ARF and RHD

- In Australia in 2009-10, there were 2,666 hospitalisations for ARF and RHD, 0.6% of all CVD hospitalisations. Rates of hospitalisation among females were 1.3 times the rates of hospitalisations among males. The NT had the highest levels of hospitalisations (86 per 100,000) compared to Qld (15 per 100,000) and WA (12 per 100,000).

- During 2008-10, there were 702 hospitalisations in Australia for ARF and RHD for Indigenous people (4% of total hospitalisations for ARF and RHD). After age-adjustment, hospitalisation rates for ARF and RHD were 6.8 times higher for Indigenous people than for their non-Indigenous counterparts.

### Deaths from ARF and RHD

- In Australia in 2007-2009, there were 12 deaths recorded with the underlying cause of ARF, but no information was recorded about the Indigenous status of these deaths. During 2004-2007, when Indigenous status was recorded, there were 13 deaths recorded in NSW, Qld, WA, SA and NT; less than one-third of these deaths recognised as being of an Indigenous person.
- In Australia in 2007-2009, there were 897 deaths with RHD as the underlying cause, 0.6% of all CVD deaths, and 0.2% of all deaths. Females had higher rates of deaths from RHD with 1.5 times as many deaths than males. This is consistent with the higher levels of RHD and hospitalisation of RHD among females.
- During 2006-2010, RHD was the cause of 90 Indigenous deaths at a level 4.7 times higher than that of non-Indigenous people. More than two-thirds or 61 of these deaths were of Indigenous females.

### Management

- Indigenous people do not receive the same level of primary prevention and management, emergency and acute care, rehabilitation, ongoing management, and secondary prevention care for cardiovascular disease (CVD) as do non-Indigenous people.
- Many Indigenous people with a past history of ARF or RHD do not receive the recommended levels of penicillin prophylaxis. In 2002-2006, only 18% of eligible people in far north Queensland and the Kimberley region of WA received 80% or more of their recommended doses in the preceding 12 months; the low levels of prophylaxis are reflected in the proportion of ARF notifications classified as recurrences – 27% of cases for the Top End of the NT and 30% for central Australia.
- An audit of control programs in far north Queensland and the Kimberley region of WA reported that only 20% of RHD patients had been prescribed an anticoagulant, 55% had been reviewed by a specialist in line with local management guidelines, 61% had had a timely echocardiogram, and 22% had undergone valve surgery.

## Introduction

In Australia, acute rheumatic fever (ARF) and rheumatic heart disease (RHD) continue to affect Indigenous<sup>2</sup> people disproportionately and represent the greatest disparity in cardiovascular health conditions between Indigenous and non-Indigenous people [5-10]. ARF remains almost exclusively experienced by Indigenous people in Australia today [1]. Indigenous children and young adults in Australia are the most affected by this disease, with rates being among the highest in the world [1, 8, 9, 11].

This review focuses on the burden of ARF/RHD for Indigenous people in Australia. It addresses overall prevalence, hospitalisation and mortality, and the factors contributing to this burden. This review also provides detailed information about the disease, its historical context, diagnosis, and guidelines. The review also considers: factors contributing to ARF/RHD; prevention and rehabilitation, and policies and strategies.

## Acute rheumatic fever and rheumatic heart disease

ARF is an inflammatory disease that can cause damage to the heart muscle, valves and lining; it can also affect connective tissues in the brain and skeletal system [10]. ARF is commonly caused by an untreated bacterial throat infection, particularly group A streptococcus [8, 9, 11, 12]; more recently, there is growing debate about the causative role of streptococcal skin sores [8-14]. Research in the Top End of the Northern Territory (NT) found that of all Indigenous people with ARF who had throat swabs, 4% were positive for group A streptococcus, thus highlighting the possibility that the cause might be from another type of streptococcus in skin sores [13, 15]. Long-term damage of the heart valves and heart muscle following cases of ARF leads to RHD.

## History and socioeconomic context

Worldwide, reported cases of ARF and RHD have decreased markedly in developed countries over the past century. During the period 1952 to 1978, notifications of ARF in Australia decreased from 6.4 per 100,000 to 0.3 per 100,000 [16]. New cases among the Australian population are now rare [13]; this has been attributed most commonly to improved living conditions and treatment

with antibiotics [13, 17]. Rates among the Indigenous population have not decreased to the same proportion as that among other Australians, with rates of ARF for Indigenous people in the Top End of the NT among the highest in the world. The World Heart Federation (WHF), which has recognised the disease as afflicting marginalised communities, has recently set a strategic goal to reduce worldwide deaths from the disease among those aged 25 years by 25% by 2025 [18].

Socioeconomic factors, including living conditions (such as poor hygiene, inadequate clean water and sewerage, and overcrowding) and inaccessible health services, are linked to cases of ARF [8-10, 13]. The relatively poor living conditions of many Indigenous people, particularly those living in remote areas, contributes to the high levels of ARF among Indigenous people.

There is a correlation between cases of ARF/RHD and living conditions [8, 9, 11], but these analyses do not address possible considerations of heredity or genetic factors. Some research debates this correlation and concludes that the link between ARF/RHD and living conditions is not significant, and that other factors need to be considered [12, 19].

## Diagnosis

There is currently no simple way of testing for ARF (such as by a blood test), and there is no definitive single symptom or sign of the disease. The disease is diagnosed using a set of criteria, comprising a combination of major and minor symptoms, following a group A streptococcal (GAS) infection (cases where there is no evidence of a previous GAS infection can only be considered probable cases of ARF) (see below guidelines) [20-23].

GAS infections can often cause pharyngitis. Prompt diagnosis and treatment of pharyngitis with antibiotics, is essential to prevent the development of ARF [23]. Diagnosis follows a positive throat swab culture for *Streptococcus pyogenes*.

## Guidelines

Guidelines for the diagnosis of ARF, first established in 1944, are referred to as the Jones criteria [20-22]. The criteria, which have been modified on several occasions (including 1956, 1965, 1984 and 1992) in response to changes in disease characteristics, provide clearer definitions that assist in the assessment of borderline cases [20-22]. With each modification, the guidelines became more specific but less sensitive; in some cases they became less appropriate for use in populations with a high incidence (such as among Indigenous Australians).

2 The term Indigenous here refers to the two Indigenous population groups of Australia, Australian Aboriginal people and Torres Strait Islanders.



The World Health Organization (WHO) published guidelines in 2004 [23]; the Australian guidelines were developed in 2005 [1, 24]. Guidelines for the diagnosis and management of RHD (including ARF) in Australia were based on a review by the National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand, and informed by the National Health and Medical Research Council [24]. The 2nd edition of these guidelines was released in 2012 [24].

The Australian guidelines, which contain criteria for use with high-risk and low-risk populations, also include slightly different criteria for primary and recurrent episodes [1]. They were developed in response to concerns that the established criteria may not be sensitive enough for use with high incidence populations, such as Indigenous Australians. For initial episodes of ARF, the Australian guidelines support a definite diagnosis if two major or one major and two minor manifestations are present as well as evidence of an earlier GAS infection (without evidence of a previous GAS infection only a probable ARF diagnosis can be made). For recurrent cases of ARF the criteria provide for the inclusion of three minor manifestations as another alternative.

#### Box 1: Manifestations of ARF

For high-risk groups, major manifestations are inclusive of carditis (including sub-clinical evidence of rheumatic valvular disease on echocardiogram), polyarthritis or aseptic monoarthritis or polyarthralgia, chorea, erythema marginatum, and subcutaneous nodules [1]. Minor manifestations for high-risk groups include fever, erythrocyte sedimentation rate (ESR) greater than or equal to 30mm/h or C-reactive protein (CRP) level greater than or equal to 30mg/L, and prolonged PR interval on electrocardiogram (ECG). For suspected cases of ARF, the Australian guidelines recommend further investigations, including biochemical testing, blood culture, electrocardiogram, chest x-ray, throat swab, and streptococcal serology.

## Extent of acute rheumatic fever and rheumatic heart disease

### Incidence and prevalence

#### Acute rheumatic fever

##### Box 2: Sources of information about ARF and RHD in Australia

Notifications of ARF began in the Northern Territory (NT) in 1994, followed by Queensland (Qld) in 1999, and Western Australia (WA) in 2007. ARF is currently not a notifiable disease in any other state or territory [25].

Information on cases of ARF and RHD reported in this review is mainly derived from registers in the Top End of the NT and central Australia<sup>3</sup> [9, 10, 24, 26]. These registers have been in effect since 1997 and 2000 respectively and have now amalgamated to a state-wide program (2007) [25]. Similar programs have been set up more recently in Far North Qld (2006) and WA (2009). The programs gather information about existing, past, new and recurrent cases of ARF, and RHD [10, 26]. The programs seek to facilitate improved follow-up for patients (including reviews), and to monitor the adherence to treatment regimens, such as primary and secondary prophylaxis [11].

3 Including parts of the NT and comprising neighbouring parts of SA and WA.

#### Northern Territory

In 2007-2010, there were 221 notifications of new and recurrent cases of ARF in the NT (Table 1) [27]. There were more cases recorded in the Top End, 160 cases, than in central Australia, 61 cases [27]. Almost two-thirds (61%) of the Indigenous notifications were for children aged 5-14 years, with a rate of 2.3 cases per 1,000 population. The rates for ARF were highest for Indigenous females in the 5-14 years age group (2.8 cases per 1,000) (Table 1) [27]. Indigenous females accounted for 139 (63%) of the notifications for ARF and Indigenous males for 82 notifications (37%).

**Table 1. Notifications of acute rheumatic fever among Indigenous people, by sex and selected age groups, Northern Territory, 2007-2010**

Sex	Age groups			All ages	Rate ratio
	5-14	15-24	25-34		
Males					
Number	54	21	3	82	70.1
Rate	1.8	0.8	0.1	0.7	
Females					
Number	81	32	14	130	74.6
Rate	2.8	1.3	0.6	1.1	
Persons					
Number	135	53	17	221	75.0
Rate	2.3	1.0	0.4	0.9	

Source: Australian Institute of Health and Welfare, 2013 [27]

Notes: 1 Rates are per 1,000  
2 Age-specific figures calculated using the average number of registrations for 2007-2010 divided by the 2006 estimated resident Indigenous Australian population for the Top End, NT and central Australia  
3 All ages includes 0-4 years and people aged 36 years or older  
4 Rate ratio is the Indigenous rate divided by the non-Indigenous rate.

Overall, Indigenous people experience levels of ARF more than 75 times those of non-Indigenous people [27]. In 2007-2010, the Indigenous:non-Indigenous rate ratio for ARF was highest among females living in the Top End (78); the lowest statistically significant difference was found among females living in central Australia (54) [27].

Annual notification rates remained steady until 1999, and then fluctuated over the first decade of this century; rates in 2010 were similar to those in 1996 (25 and 26 notifications per 100,000, respectively) [27].

## Queensland

In 2009-2011, there were 178 notifications of new and recurrent cases of ARF in Qld [25]. Of these cases, 160 or 90% were Indigenous people. Recurrent cases made up 10% of all cases. Almost two-thirds (60%) of the Indigenous notifications were for children aged 5-14 years. Proportions of notifications were similar among females and males across all age groups (49% and 51% respectively). In the period 1999-2011, there were 502 cases of ARF in Qld, [25]. Average annual rates were much lower in Qld than in the NT (1 and 26 notifications per 100,000 respectively).

The more detailed information available for 2004-2009 reveals that the proportion of new and recurrent cases of ARF in the north Qld Indigenous population was higher for females than for males (females accounted for 111 (57%) of the 194 people responsible for 203 cases notified in 2004-2009) (Table 2) [28]. Children aged 5-14

years accounted for 131 (65%) of all notifications. More than one-quarter (27%) of notifications were recurrences. The overall annual incidence rate was 0.6 notifications per 1,000 population; the rate for children aged 5-14 years was 1.6 per 1,000. The total numbers of notifications and the annual incidence rates increased between 1999-2004 and 2004-2009, both overall and for children aged 5-14 years

**Table 2. Notifications of acute rheumatic fever among Indigenous people, by sex and selected age groups, north Qld, 1999-2004 and 2004-2009**

	1999-2004	2004-2009
Total notifications	144	203
5-14 years (% total cases)	93 (65%)	131 (65%)
Annual incidence	0.5	0.6
Annual incidence (5-14 years)	1.2	1.6
Median age (years)	12.0	12.6
Female (% total persons)	67 (50%)	111 (57%)
Recurrences (% total cases)	33 (23%)	54 (27%)

Source: Hanna J, Clark M, 2010 [28]

Notes: 1 Annual incidence is per 1,000 population  
2 Annual incidence (5-14 years) is per 1,000 children  
3 Time periods are mid 1999-mid 2004 and mid 2004-mid 2009

## Western Australia

In 2010-2011, there were 21 notifications of new and recurrent cases of ARF in WA [25]. All of these cases were of Indigenous people. Almost three-fifths (57%) of the notifications were for children aged 5-14 years. The levels of ARF were highest for Indigenous males in the 5-14 years age group. Indigenous males accounted for more notifications for ARF than females among all age groups.

An earlier analysis of ARF in the Kimberley region of WA found that there were 96 notifications of new and recurrent cases in 1988-1992. All except one of the 81 people responsible for these notifications were Indigenous (Table 3) [29]. Over one-half (52%) or 42 of these were Indigenous females; Indigenous children aged 5-14 years accounted for 52% (50) of the total notifications. Recurrent cases made up 38% of the total notifications. The annual incidence rate for Indigenous people was 2.4 per 1,000. The rate for Indigenous children aged 5-14 years was 3.8 per 1,000.

**Table 3. Notifications of acute rheumatic fever among Indigenous people, by sex and selected age groups, Kimberley region of WA, 1988-1992**

	1988-1992
Total notifications	96
5-14 years (% total cases)	50 (52%)
Annual incidence	2.4
Annual incidence (5-14 years)	3.8
Median age (years)	13.3
Female (% total persons)	42 (52%)
Recurrences (% total cases)	37 (38%)

Source: Richmond P, Harris L, 1998 [29]

Notes: 1 Annual incidence is per 1,000 population

## Rheumatic heart disease

### Northern Territory

In line with the much higher notification rates of ARF, Indigenous people experience far higher levels of RHD than do non-Indigenous people [10]. In 2010, there were 1,479 cases of RHD on the register in the NT [25, 27]. Almost all cases involved Indigenous people (1,379 cases or 93%). After adjusting for the different population age structures, the prevalence among Indigenous people was 26 times higher than that among non-Indigenous people (

Table 4) [27]. The prevalence among Indigenous people was high across all age groups particularly the 35-64 year age groups. For non-Indigenous people, the prevalence was the highest among those aged 65 years or older [25]. The greatest disparities between Indigenous people and non-Indigenous people were in the under 35 year age groups.

Overall, the age-standardised figures were 18 for Indigenous males and 33 for Indigenous females (Table 5)[27]. Around one-third of all cases were Indigenous males and two-thirds Indigenous females. There was substantial disparity between Indigenous people and non-Indigenous people with the overall age-standardised rate ratios, 28 for males and 24 for females [26]. The greatest differences were seen among the 15-24 and 25-34 years age groups with rates ratios 137 and 140 respectively<sup>4</sup>.

- 4 The ratio for the 0-14 group was not available, but, given the high prevalence in this age group, the disparity is likely to be high.

**Table 4. Numbers and prevalence (%) of rheumatic heart disease among Indigenous people, and Indigenous:non-Indigenous ratios, by sex and age group, NT, 2010**

Sex	Age groups							All ages
	0-14	15-24	25-34	35-44	45-54	55-64	65+	
Males								
Number	53	121	108	92	62	26	13	475
Prevalence	4.6	19.0	21.5	22.6	23.9	21.3	18.5	17.8
Ratio	.....	100.1	139.9	76.4	32.7	47.6	5.9	28.2
Females								
Number	68	184	215	198	137	67	35	904
Prevalence	6.2	29.3	39.8	46.1	47.1	43.6	30.3	32.6
Ratio	.....	137.5	123.1	79.5	42.9	14.3	5.2	24.4
Persons								
Number	121	305	323	290	199	93	48	1379
Prevalence	5.4	24.1	31.0	34.6	36.2	33.7	25.8	25.7
Ratio	.....	120.1	131.1	80.6	40.0	21.8	6.0	27.3

Source: Australian Institute of Health and Welfare, 2013 [27]

Notes: 1 The prevalences for 'All ages' have been standardised

2 Age-specific figures were calculated using the 2006 estimated resident Indigenous Australian population for the NT

3 Ratio is the Indigenous prevalence divided by the non-Indigenous prevalence.

In the Top End of NT and central Australia, there were 1,379 cases of RHD on the register in 2010; there were nearly three times as many cases recorded in the Top End (1,154) than in central Australia (325) [10, 27]. Almost all cases involved Indigenous people: 93% in the Top End and 94% in central Australia. Registered cases of RHD were 36 times higher for Indigenous males and 28 times higher for Indigenous females in the Top End of the NT than for their non-Indigenous counterparts (Table 5)[27]. In central Australia, registered cases were 13 times higher for Indigenous males and 17 times higher Indigenous females than those for non-Indigenous males and females. The prevalence of RHD was highest among Indigenous females, 3.7% in the Top End of the NT (Table 5)[27].

**Table 5. Prevalence (%) of rheumatic heart disease by Indigenous status and sex, Top End NT and central Australia, 2010**

Area	Indigenous status		Ratio
	Indigenous	Non-Indigenous	
Top End, NT			
Males	2.1	0.1	35.6
Females	3.7	0.1	27.7
Persons	2.9	0.1	32.4
Central Australia			
Males	1.2	0.1	12.8
Females	2.4	0.1	17.4
Persons	1.8	0.1	16.3
Northern Territory			
Males	1.8	0.1	28.2
Females	3.3	0.1	24.4
Persons	2.6	0.1	27.3

Source: Australian Institute of Health and Welfare, 2013 [27]

Notes: 1 Figures are directly age-standardised using the 2001 Australian standard population  
2 Rate ratio is Indigenous:non-Indigenous. All ratios are significant at the p<0.05 level

## Queensland

In 2012, there were 939 cases of RHD recorded in Qld. [25]. Almost all cases involved Indigenous people (845 cases or 90%). Almost two-thirds (63%) of recorded cases were among females, particularly in the over 25 years age groups (66%). Among males, the highest levels of recorded cases of RHD were found among those aged less than 25 years (55%).

## Western Australia

In 2011, in WA, there were 158 cases of RHD recorded [25]. All cases involved Indigenous people. Almost two-thirds (61%) of recorded cases were of Indigenous females. The highest level was recorded for the people aged less than 25 years (42%), followed by the 25-44 year age groups (36%), and the 45years and over age groups (22%).

## Hospitalisation

In the two-year period July 2008 to June 2010, , ARF and RHD were responsible for 718 admissions to hospital of Indigenous people living in in NSW, Vic, WA, SA and the NT (Table 6) [26, 27]. The hospitalisation rate of Indigenous people for ARF and RHD was almost seven times higher than that for other Australians. The hospitalisation rate for Indigenous females (0.9 per 1,000) was higher than that for Indigenous males (0.4 per 1,000). Indigenous females were hospitalised for ARF and RHD at a level eight times that of other Australian females and Indigenous males five times the level of other Australian males. ARF and RHD accounted for 0.6% of all CVD hospitalisations; levels were highest in the NT (86 per 100,000) compared with Qld (15 per 100,000) and WA (12 per 100,000) [25].

**Table 6. Hospitalisations of Indigenous people for acute rheumatic fever and rheumatic heart disease, by sex, NSW, Vic, Qld, WA, SA and NT, July 2006 to June 2008 and July 2008 to June 2010**

Sex	2006-08	2008-10
Male		
Number	274	249
Rate	0.5	0.4
Rate ratio	5.3	4.8
Female		
Number	428	469
Rate	0.9	0.9
Rate ratio	8.2	8.3
Persons		
Number	702	718
Rate	0.7	0.7
Rate ratio	6.9	6.8

Source: Australian Institute of Health and Welfare, 2011, 2013 [26, 27]

Notes: 1 Rates are per 1,000  
2 Figures are directly age-standardised using the 2001 Australian standard population  
3 Rate ratio is the Indigenous rate divided by the non-Indigenous rate.

## Hospital procedures

Indigenous people are more likely to be hospitalised for ARF and RHD than are non-Indigenous people, and less likely (around 40%) to undergo a procedure once admitted [25]. Between 2007-08 and 2009-10, there were 675 hospitalisations of Indigenous people in Australia for ARF and RHD. Rates for hospitalisation among Indigenous people were 5.4 times as high as non-Indigenous people, however Indigenous people were less likely to receive a heart valve procedure 28% compared with 49% among non-Indigenous people.



## Hospital expenditure

Hospital expenditure for all admitted Indigenous people during 2008-09 was \$1470.5 million [25]. ARF/RHD made up 0.4% (\$5.9 million) of the total amount of expenditure for Indigenous people, and per person this figure was 4.3 times as high as that of non-Indigenous people (\$11 per person compared with \$2 per person respectively).

## Avoidable deaths

There were 87 avoidable deaths of Indigenous people from RHD during the period 2006-2010 (Table 7)[27]. After age-adjustment, the rate for avoidable deaths from RHD was more than 13 times higher for Indigenous people than for non-Indigenous people.

**Table 7.** *Avoidable mortality from rheumatic heart disease, by Indigenous status, NSW, Qld, WA, SA and NT, 2006-2010*

	Indigenous	Non-Indigenous
Number	87	290
Percent	1.3	0.3
Per 100,000	5.2	0.4
Rate ratio	13.3	.....

Source: Australian Institute of Health and Welfare, 2013 [27]

Notes: 1 Figures are directly age-standardised using the 2001 Australian standard population  
2 Rate ratio is the Indigenous rate divided by the non-Indigenous rate.  
3 Percent is of all avoidable causes of deaths

## Mortality

ARF was the underlying cause of 12 deaths in Australia during 2007-2009, but no information was recorded about the Indigenous status of these deaths [25]. During 2004-2007, there were 13 deaths recorded in NSW, Qld, WA, SA and NT; less than one-third of these deaths were identified as being of Indigenous people.

During 2006-2010 RHD was the cause of 90 Indigenous deaths at a rate 4.7 times higher than that of non-Indigenous people (Table 8) [26, 27]. More than two-thirds (61) of these deaths were of Indigenous females. Recorded deaths among Indigenous females were 7.7 per 100,000 and Indigenous males were 3.3 per 100,000. Indigenous females suffered a greater disparity than Indigenous males with their non-Indigenous counterparts: rate ratios of 5.3 and 3.5 respectively.

The actual numbers of deaths from RHD have decreased between the periods 2002-2006 and 2006-2010, the rates and rate ratios have also decreased for both Indigenous males and females [26]. Deaths per 100,000 for Indigenous males decreased from 6.2 to 3.3

during this time, and for Indigenous females decreased from 16.0 to 7.7. The rate ratios also decreased from 6.1 to 3.5 for Indigenous males and 10.9 to 5.3 for Indigenous females.

**Table 8.** *Deaths of Indigenous people from rheumatic heart disease, by sex, NSW, Qld, WA, SA and NT, 2002-2006 and 2006-2010*

Sex	2002-2006	2006-2010
Male		
Number	30	29
Rate	6.2	3.3
Rate ratio	6.1	3.5
Female		
Number	67	61
Rate	16.0	7.7
Rate ratio	10.9	5.3
Persons		
Number	97	90
Rate	11.5	5.7
Rate ratio	9.0	4.7

Source: Australian Institute of Health and Welfare, 2011,2013 [26, 27]

Notes: 1 Rates are per 100,000  
2 Data recorded for the period 2002-2006 does not include NSW data due to inadequate levels of Indigenous identification at that time.  
3 Figures are directly age-standardised using the 2001 Australian standard population  
4 Rate ratio is Indigenous:non-Indigenous. All ratios are significant at the p<0.05 level

## Age-specific death rates

Over one-half of deaths of Indigenous people from RHD occurred in the 25-54 years age group; the highest number of deaths was for people aged 25-34 years with 22 deaths recorded (Table 9)[27]. Deaths from RHD among people aged 15-24 years accounted for 27% of all CVD deaths for that age group.

**Table 9. Age-specific deaths from rheumatic heart disease among Indigenous people, by age group, NSW, Qld, WA, SA and NT, 2004-2008**

	Under 1	1-4	0-4	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75+	All ages
Rheumatic	0	4	4	.....	10	22	18	15	12	5	.....	90
heart disease	0%	50%	16%	.....	27%	16%	5%	3%	2%	1%	.....	3%
Total circulatory disease	16	8	24	6	36	135	388	559	546	527	703	2925

Source: Australian Institute of Health and Welfare, 2013 [27]

Notes: 1 Percent (%) is the percentage of all circulatory age specific deaths

From 1979-1996, in Australia, deaths rates for RHD reduced by more than 50% from 2.0 to 0.9 per 100,000 for males and 3.1 to 1.1 per 100,000 for females [25]. Following this was an increase of 0.8 deaths per 100,000 up to 1997 before figures stabilised in 1998. During the 31 year period, up to 2009, deaths rates have continued to be higher for females.

## Prevention and management

Prevention and treatment programs for ARF and RHD in Australia have increased in recent years, and their focus is moving towards a coordinated national approach [8, 9, 11, 12, 31, 32]. The Rheumatic fever strategy provides a coordinated program for the prevention and treatment of ARF and RHD among Indigenous people, particularly children [31, 32]. Prevention of ARF and RHD occurs at a primordial, primary, secondary and tertiary level, each one targeting different stages of the disease, from the prevention of new cases of ARF to the reduction of disability and premature death from RHD.

The prevention and treatment of ARF and RHD involves two complementary parts: (1) the surveillance, identification and registration of new and recurrent cases, and education for health professionals [24, 31, 33]; and (2) working with the family and local community of those with ARF/RHD, through measures such as health promotion, education, and supporting adherence to primary and secondary prophylaxis [8, 9, 11, 12, 24, 31, 33].

Further prevention measures can include training of health care providers and the involvement of schools and wider communities to work together and play a role in the prevention and control of ARF and RHD [23].

### Primordial prevention

ARF and RHD are preventable causes of morbidity and mortality among Indigenous people; and organised primary health care is essential for their control [24]. Primordial prevention requires improvements in socioeconomic conditions and housing, which would lower the carriage and transmission of group A streptococci

(the causative agent for ARF), and reduce the need for early detection and treatment with antibiotics to prevent ARF [24, 34]. There is also a great need for health care providers to concentrate on meeting the needs of Indigenous people through better prevention, diagnosis, service delivery and access to care [35, 36].

Primordial prevention requires broad political commitment to addressing the social, economic and environmental inequities experienced by Indigenous people [1, 24, 35]. Improvements in the interrelated areas of housing, education and employment are required to address chronic disease, rather than concentrating mainly on health service delivery [37]. Even after allowing for the effects of behavioural and biomedical risk factors (such as smoking, physical inactivity and obesity); socioeconomic variables remain independently associated with the risk of death from CVD [38]. Limitations in the delivery of holistic care seem to be due to a lack of structure between services of the commonwealth, and state and territory governments in this area. Many areas affecting health, including education, employment, social services, and transport are not greatly influenced by the health sector, and therefore national health policies for Indigenous people require much greater integration [9, 13, 24, 39, 40].

### Primary prevention

Primary prevention of ARF and RHD starts with the prevention, prompt diagnosis and treatment of group A streptococcus upper respiratory tract infection pharyngitis/tonsillitis with antibiotics (referred to as primary prophylaxis) [23, 24]. This can prevent an initial attack of ARF from developing, and can help to control the spread of infection. Group A streptococcal pharyngitis can be diagnosed with throat sample cultures taken from swabs of suspected cases. Effective oral antibiotic treatment, such as penicillin, aims to eradicate group A streptococcal in the upper respiratory tract and it can prevent the development of ARF if the treatment commences within 9 days of the initial symptoms.

There is considerable potential for reduction in the levels of ARF and RHD among Indigenous people, but there must be committed application of the knowledge currently available [1, 24]. As well as

action addressing the various behavioural risk factors, attention also needs to be directed to the adverse social, economic, and environmental conditions of many Indigenous people.

## Secondary prevention

Secondary prevention measures are used with individuals who have established RHD, to help prevent further progression of the disease [24]. Secondary prevention is through treatment with antibiotic injections; this is referred to as secondary prophylaxis. It is important in preventing recurrences of group A streptococcal infections and recurrent cases of ARF, which can further damage the heart and increase the risks of establishing RHD [23, 24]. In order to be effective, a high level of prophylaxis must be achieved with regular long-term treatment with penicillin. Four-weekly doses of antibiotics are the treatment of choice. In patients considered to be at high risk, 3-weekly administration may be appropriate. The benefits of a shorter duration between each course of medication are offset by the difficulties of achieving good adherence to the regimen. The appropriate duration of secondary prophylaxis is determined by age, time since the last episode of ARF, potential harm from recurrent disease, presence and severity of RHD, number of previous attacks, family history, socioeconomic status, and risk of streptococcal infection in the area [23, 24, 41]. Treatment is usually continued for approximately 10 years or until the age of 21 years, whichever is longer [8, 9, 11, 12, 24].

In 2009, nearly one-quarter (23%) of Indigenous people registered with the ARF/RHD program adhered to secondary prophylaxis at a level more than 80% of their required doses [26]. Two-fifths (41%) met 50-80% of required doses, and one-third (36%) met less than 50% of required doses. Adherence was greatest in the Top End of the NT with one-quarter (25%) meeting over 80% of required doses, compared with almost one-fifth (17%) in central Australia.

## Tertiary prevention

Tertiary prevention includes measures used with individuals who have established RHD to help reduce symptoms and disability, as well as prevent premature deaths [24]. For Indigenous people with established RHD, access to cardiac surgery and other medical treatment may be important. This form of prevention is considered to be the least cost effective of all the prevention initiatives for this disease [42, 43].

## Rheumatic fever strategy

The Rheumatic fever strategy aims to address ARF and RHD among Indigenous people, particularly children. It provides a coordinated program including: prevention and treatment; funding for state-based registers and control programs in the NT, WA and Qld; and a national coordination unit, RHD Australia. The strategy builds on the Rheumatic heart disease control program, which was established in the Top End of the NT in 1997 and extended to include central Australia in 2000 (where it became fully operational in 2002) [24, 31, 32].

The keys outcomes of this strategy include improvements to clinical responses, and support for monitoring and treatment of ARF and RHD through the establishment of a national data collection system. These outcomes will be achieved by: conducting surveillance; identifying and registering new and recurrent cases; providing education and training for health care providers; improving clinical care and follow-up; providing education and health promotion to clients, families and the community; and supporting the uptake of and adherence to secondary prophylaxis [24, 31, 33].

## Management

The management of ARF and RHD involves both prevention of recurrent cases of ARF and the appropriate, timely medical and surgical management of those with RHD [24, 44].

ARF can be difficult to diagnose, but early diagnosis of ARF is essential to ensure that preventive measures can be implemented in a timely manner to lessen the risk of developing recurrent ARF and RHD [44]. Suspected cases of ARF should be referred to hospital as soon as possible after the onset of symptoms. The use of echocardiography to identify evidence of carditis has recently been included as a criterion in the national guidelines; suspected ARF cases should now have an echocardiogram shortly after hospital admission [44-46]. Other investigations for suspected ARF can include: white blood cell count; erythrocyte sedimentation rate; C-reactive protein; blood cultures; electrocardiogram; chest x-ray; throat swab; and anti-streptococcal serology. The importance and urgency of an accurate diagnosis and prompt treatment of ARF can be overlooked by medical staff, particularly in areas where occurrences of ARF are rare.

The proportion of ARF notifications classified as recurrences is an important indicator of the effectiveness of ARF control programs [47]. The proportion of recurrences has probably declined in recent years, but still comprised 27% of cases for the Top End of the NT and

30% for central Australia in 2002-2006 [10]. These levels confirm ongoing shortcomings with secondary prophylaxis programs, which are most effectively implemented very early in the natural history of RHD; with effective prophylaxis, many people with mild RHD may have no detectable disease 5 to 10 years later [24, 40]. The main shortcoming with current secondary prophylaxis programs is that many people with a past history of ARF or RHD do not receive the recommended levels of penicillin prophylaxis, optimally with intra-muscular benzathine penicillin G [24]: an audit of control programs in far north Queensland and the Kimberley region of WA found that only 18% of eligible people had received 80% or more of their doses in the preceding 12 months [48].

Adherence to secondary prophylaxis can be impacted by the availability and accessibility of health services, particularly in remote areas [44]. Studies conducted in the NT found that improved adherence occurred when: patients felt a sense of belonging to a health clinic; dedicated staff administered treatment; and active follow-up was made by clinic staff. Barriers impacting on the delivery of injections included: pain of injection (particularly for young people); high staff turnover; mobility of patients; size and complexity of the community and its health service; as well as a lack of supportive infrastructure. Potential strategies to improving the adherence to injections could include: increased use of Aboriginal Health Workers; regular contact with health clinics; recall and reminder systems; centralised co-ordination; promoting the importance of timely treatment through health education for staff, patients and families; support that extends beyond community boundaries [44, 49]. The various possible manifestations of RHD – damage to the heart valves and associated structures, cardiomyopathy, atrial fibrillation, systemic embolism, TIAs and strokes, and infective endocarditis [50] – require ongoing monitoring and appropriate medical and surgical management. For people with established RHD, best practice requires: secondary prevention; monitoring of anticoagulant therapy (for people with AF and/or mechanical prosthetic valves); access to oral healthcare; access to echocardiography; access to appropriate specialist(s); and access to cardiothoracic and interventional cardiology services [24].

There is no comprehensive information about how these requirements are being addressed, but an audit of control programs in far north Queensland and the Kimberley region of WA reported that only 20% of RHD patients had been prescribed an anticoagulant, 55% had been reviewed by a specialist in line with local management guidelines, 61% had had a timely echocardiogram, and 22% had undergone valve surgery [48].

The progression of valve damage is much more rapid among Indigenous patients with RHD than among their non-Indigenous counterparts: the mean age for 45 Indigenous patients from the NT who had undergone mitral valve repair procedures at the Flinders Medical Centre was 23 years [51]. Around 45% of the Indigenous patients and 4% of non-Indigenous patients were less than 25 years. Despite their youth, many of the Indigenous patients had major valve destruction as well as substantial comorbidity. Short-term results were similar for Indigenous and non-Indigenous patients, but long-term outcomes were worse for Indigenous patients than for their non-Indigenous counterparts.

## Concluding comments

The extent of ARF and RHD is still very high among some Indigenous people in Australia; in comparison, the conditions are very uncommon among non-Indigenous people. Hospitalisations and deaths from ARF and RHD continue to burden Indigenous people at a rate around seven times the rate for other Australians. Being linked to poverty, poor living conditions and limited access to health services, ARF and RHD are largely preventable, as evidenced by the very low levels among non-Indigenous Australians (and in other developed countries).

The recently established national coordination strategies for the prevention and treatment of ARF and RHD emphasise the great importance of primary and secondary prophylaxis. Early diagnosis is essential to curb the risk of developing recurrent ARF and RHD. Secondary prophylaxis generally involves four-weekly administration of intramuscular benzathine penicillin, but the long-term adherence required can be problematic due to: mobility of patients; the pain of injection (particularly for young people); and levels of service provision. And, of course, improvements in the living conditions of Indigenous Australians – and their access to health services – are essential to prevent new cases of ARF and RHD and reduce the risks of disease progression.

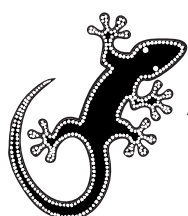
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## Australian Indigenous HealthInfoNet

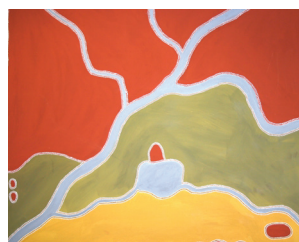
The Australian Indigenous HealthInfoNet is an innovative Internet resource that contributes to 'closing the gap' in health between Indigenous and other Australians by informing practice and policy in Indigenous health.

Two concepts underpin the HealthInfoNet's work. The first is evidence-informed decision-making, whereby practitioners and policy-makers have access to the best available research and other information. This concept is linked with that of translational research (TR), which involves making research and other information available in a form that has immediate, practical utility. Implementation of these two concepts involves synthesis, exchange and ethical application of knowledge through ongoing interaction with key stakeholders.

The HealthInfoNet's work in TR at a population-health level, in which it is at the forefront internationally, addresses the knowledge needs of a wide range of potential users, including policy-makers, health service providers, program managers, clinicians, Indigenous health workers, and other health professionals. The HealthInfoNet also provides easy-to-read and summarised material for students and the general community.

The HealthInfoNet encourages and supports information-sharing among practitioners, policy-makers and others working to improve Indigenous health – its free on line yarning places enable people across the country to share information, knowledge and experience. The HealthInfoNet is funded mainly by the Australian Department of Health and Ageing. Its award-winning web resource ([www.healthinfonet.ecu.edu.au](http://www.healthinfonet.ecu.edu.au)) is free and available to everyone.

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